



ALERT

News from the UFMCC
on AIDS Legislation, Education, Research and Treatment.

September 1994

AIDS Ministry at MCC of The Ozarks

Rev. Teri DeMarco, Pastor of MCC of the Ozarks in Fayetteville, Arkansas, reports, "In November, 1993, we had 58 members. And in the few months since then, we've lost 20 people to the complications of AIDS, heart attacks, and cancer. Members are numb with grief. So I brought in a grief seminar, and they've all become caretakers. They're taking care of each other. They're really in tune with each other, and it's a direct result of the deaths. They're drawing together. For the first time in our history, 14 people went to our District Conference. On Sundays, I can't get them out of here!"

AIDS Ministry at MCC of the Ozarks got started in 1988, with the arrival of Rev. DeMarco in Fayetteville. She had done her student clergy work in Fayetteville, a town of some 42,000, in the early 80's. Rev. Brad Anderson was also student clergy there at the time. She subsequently went to Shreveport, Louisiana, but was called back to MCC



Rev. Teri DeMarco

of the Ozarks as pastor in 1988. She was made a member of the Board of Directors of the Washington County AIDS Task Force before she even arrived in Fayetteville. She encouraged

church members to get involved with volunteer work with the AIDS Task Force, and now at least half of the congregation's members are involved. And many of the clients of the Task Force are members of the church. Members of the congregation are involved in direct services, the hotline, advertising, and education. But Rev. DeMarco's greatest involvement is with direct services. "We cook, we clean, we take them shopping, and we try to meet every one of their needs. Sometimes we just go and let them yell at us. We get them tickets to plays, we get them to the quilt. We've ironed out all of the problems of getting people connected to the system, and getting through the process. I do many, many memorial services."

Rev. DeMarco has also been organizing the local Interfaith AIDS Memorial Service since its inception in 1990. The service is now a cooperative venture

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UFMCC AIDS Ministry Publishes Christian Care Manual

UFMCC AIDS Ministry is proud to announce the publication of a new manual, *Christian Caring: Four Models of HIV/AIDS Ministry in the Local Church, A Manual for Pastors and Church Leaders*. Written by the Rev. Paul Tucker, director of Christian Caring at the Cathedral of Hope MCC in Dallas, Texas, the manual suggests four different models of HIV/AIDS Ministry for the local church, dealing with conditions ranging from asymptomatic to debilitation. Each of the models suggested in this useful guide has been tested in congregations that have active AIDS Ministries.

Chapter 1 deals with "The Loss of Dreams: Asymptomatic HIV." Chapter 2 is titled, "The Loss of Healthiness: Symptomatic HIV," and Chapter 3 talks about "The Loss of Independence: Debilitating HIV." The four models presented are the "HUGS Team Ministry," "H.E.L.P. Groups," a 10-week support group; "The St. Luke Team" for hospital and home visitations; and "Care Bearers: AIDS Care Team Ministry."

Not only does the manual provide training procedures and guidelines for creating each model of ministry, but Rev. Tucker also deals with stress, burnout, and caring for caregivers. The manual also provides monthly report forms for volunteers involved in each model of ministry.

To order the manual, please use the order form included in this issue of ALERT. Or send your order to UFMCC Church Services, 5300 Santa Monica Blvd., Suite 304, Los Angeles, CA 90029, USA. The manual costs US\$8.00 plus \$2.00 shipping and handling per book. California residents add 8.25% sales tax on the cost of the manual. ▼

Christian Caring

HUGS Ministry: Hearts Under Grace

1

Healing Experiences for Living Positive

2

St. Luke Team: Hospital/Home Visitation

3

Care Bearers: AIDS Care Team Ministry

4

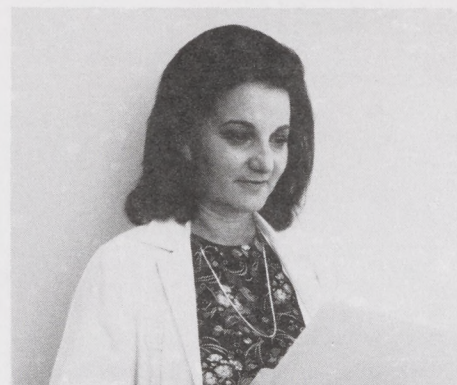
Four Models of HIV/AIDS Ministry in the Local Church
A Manual for Pastors and Church Leaders by Paul A. Tucker

Dr. Levine Awarded Coveted Medallion

Alexandra M. Levine, M.D., who has presented the HIV/AIDS medical updates at the past two General Conferences, has been awarded the University of Southern California Presidential Medallion. Dr. Levine is the eleventh person to be awarded the medallion in the history of the University.

The medallion "honors members of the USC community who have made distinctive contributions to the life of the university, both in academics and involvement in the broader life of the university." Dr. Levine is a professor of medicine and chief of hematology at the USC School of Medicine, as well as deputy clinical director of the USC/Norris Cancer Center. She has served on the faculty of the USC School of Medicine since 1977.

Dr. Levine is an internationally recognized authority in hematology, treating patients with leukemias, lymphomas, and Hodgkin's Disease. She is also world-renowned for her extensive research in AIDS and the cancers associated with HIV disease. She has been working since 1987 with Dr. Jonas Salk in the development and testing of a vaccine for HIV. ▼



Dr. Alexandra M. Levine, M.D.

Acyclovir Therapy in HIV Infection

GMHC Treatment Issues has published an article by Dave Gilden (August 1994 issue, Vol. 8, #7), citing an increasing number of studies which suggest a survival benefit from acyclovir for persons with AIDS. Gilden notes, "One physician, Marcus Conant, M.D., of San Francisco,...recommends that his patients start acyclovir as soon as they know that they are HIV-positive, a regimen he says he first tried in 1987. He thinks that acyclovir helps slow disease progression by suppressing herpes viruses, which perhaps act as a co-factor in producing AIDS. The dose he recommends is 40 mg twice a day, the standard one used to prevent recurrent herpes attacks.

"Dr. Conant's recommendation is really based on his intuitive feeling; he has little data to back him up." The article also reports that "Craig Metroka, M.D., prescribes high dose acyclovir in an effort to prevent infections with CMV (cytomegalovirus), which is a member of the herpes family that can cause blindness and death. However, studies, as of yet, have failed to confirm that acyclovir prevents CMV."

Gilden describes two past studies of acyclovir in HIV infection which left many questions unanswered. "One important issue is the proper dosage to take. Another is the duration of acyclovir's benefit."

In an analysis of the Multicenter AIDS Cohort Study (MACS), following the experiences of over 2,600 HIV-positive men in four U.S. cities, "the authors found that the use of acyclovir was not associated with a lower rate of progression to AIDS. But once one had AIDS, it reduced the risk of death in any given time period, again, by more than 40 percent." (Stein DS, et al. *Annals of Internal Medicine*. July 15, 1994; 121(2):100-8.) The article goes on to quote Neil Graham, M.D., of Johns Hopkins University and one of the authors of the report, saying, "Given the limited nucleoside analogs available, taking acyclovir now makes sense. It's well tolerated. There's now enough data to indicate that people with both AIDS and herpes virus should take it. This is the first evidence that combination therapy works."

ACTG 063, a two-year trial comparing AZT alone to AZT plus acyclovir in 400 persons with CD4 counts of less than 200, "has been languishing in the hands of the statisticians for over a year," according to Gilden. He cites "in-fighting

within the government's ACTG network and manufacturer Burroughs Wellcome's wavering financial support as two of the major obstacles to ACTG 063's completion.

"AIDS-related acyclovir trials have not been accorded priority by either private or public researchers. According to noted AIDS researcher Michael Saag, M.D., of the University of Alabama, 'People don't stand up and endorse acyclovir because no one understands why it should work.'"

The author concludes, "At this point, most of those who recommend acyclovir as a therapy for HIV-infection suggest it only in advanced disease. There is no hard data, as of yet, which supports using the drug before an AIDS diagnosis. In addition, no studies support using more than 600 to 800 mg per day, the standard herpes simplex suppressive dose. Whatever dose and point in time is best, though, acyclovir should be continued without a pause after it is started to reduce the chance of resistant virus.

"It remains to be seen whether acyclovir is useful in HIV-infected people without any evidence of herpes simplex infection, but this question may not be as important as it might seem. In the MACS study, nearly everyone who tested HIV-positive also was positive for herpes simplex. (The MACS group includes only gay men, though. Trials in other populations are needed to find out how universally helpful acyclovir could be.)

"One last question is whether acyclovir increases survival in people who are not taking AZT. As one observer wryly noted, 'One thing you'll never find out from Burroughs Wellcome is whether acyclovir is useful without AZT.'" ▼

ALERT

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Rev. Christine Oscar Honored

Rev. Christine Oscar, Pastor of St. Mary's Metropolitan Community Church in Greensboro, North Carolina, has been honored with the Mark Drum AIDS Memorial Award. Given by *Q-Notes*, a local newspaper, the award was given for her "leadership, activism, education, and commitment to issues surrounding HIV/AIDS."

Rev. Oscar has devoted much of her time to AIDS ministry for many years. She has become well-known in her community for her service to people who are sick and dying. She has spent a great deal of time in homes and hospitals, looking after the spiritual needs of many persons with HIV/AIDS. She has led workshops, created panels for the Quilt, and was one of the co-founders of the Piedmont area's "leading AIDS Service organization," the Triad Health Project.

Perhaps she is best known around UFMCC for her work in the area of grief. Many people have benefitted from her articles, published in the Gulf Lower Atlantic District's newsletter on grief, *Oil of Gladness*. A number of these articles have been reprinted in *ALERT*. In Greensboro, she conducts a day-long workshop on grief, which she has offered repeatedly to local residents. Many report that her workshop is instrumental in facilitating their healing



Rev. Christine Oscar

from grief.

Rev. Oscar was recently elected to the North Carolina Council of Church's Executive Board. As pastor of one of the largest MCC's in the Carolinas, she has gained the respect and admiration of other clergy in the area through her high visibility in AIDS Ministry.

Upon receiving her award, Rev. Oscar stated that her real reward is "being able to make a difference in people's living and dying. Once I got involved in this work, I knew I would always be involved." ▼

Pregnancy Hormone Studied For KS

A report in *GMHC Treatment Issues* (August 1994, Volume 8, Number 7) reveals that based on animal studies, "a pregnancy hormone, Human Chorionic Gonadotropin (HCG) may show promise as a treatment for Kaposi's Sarcoma (KS)...Reports circulated last year that two European women with KS had a "spontaneous resolution" of their lesions after becoming pregnant...Dr. Robert Gallo's lab at the [U.S.] National Cancer Institute duplicated this phenomenon in mice and proposed that HCG may be a useful treatment for KS."

Since that experiment, HCG has been tried in over 500 mice, and the results have been "very encouraging," according to the researchers.

Dr. Parkash Gill, a leading KS researcher, will be conducting a clinical trial of HCG in human beings with KS. This trial "will evaluate HCG as both an intralesional and intramuscular injection." The trial will be held at the University of Southern California (Parkash Gill, M.D., 213/224-6668.)

HCG, which has FDA approval for use treating infertility in women and failure of the testicles to descend in boys, may have significant side effects. "According to the *Physicians Desk Reference*, injectable HCG may cause...headache, irritability, aggressive behavior, and phallic or testicular enlargement." ▼

MCC of the Ozarks

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between 15 denominations, including the local synagogue. "We didn't start out with that many," says Rev. DeMarco. "Consciousness has been raised with other clergy. There are others starting to minister to people with HIV and AIDS now, and that really pleases me, because that was my main intent. For the first couple of years, I hit a stone wall. However, now they are more willing to serve and to work with the community." The change happened when Rev. DeMarco was "finally" invited to attend the local Ministerial Association. "Once I got in, they asked me to preach at one of their meetings. It opened doors. I used Isaiah 56:7, 'for my house will be called a house of prayer for all peoples.' For the first time in my life, I had all these pastors in front of me, taking notes! I'm proud of how far they've come."

MCC of the Ozarks grieved terribly when Rev. Brad Anderson died from the complications of HIV in 1990. He had moved to Los Angeles and was pastor of MCC Silverlake when he got sick. Teri recalls, "Brad was part of our chosen family. He was student clergy at the same time I was. The congregation raised the money to send me out to L.A. to be with Brad when he was sick. The day after I left, he died. We had such a wonderful time together. One day he shared with me, 'I would love to go for a walk.' I put him in a wheelchair, and took him all over his neighborhood, and we stopped to smell the

flowers everywhere."

One of Rev. DeMarco's gifts is her ability to relieve the fear of dying. "I've been able to give a real peace and a calm. That seems to be one of my forte's. In talking with Brad about dying, he was very afraid, and then he got over it. If that peace comes, that's healing." One of her techniques for helping people through their fear of dying is taking the fearful person through a meditation. "I do a visualization of that day, and all the cloud of witnesses cheering us on. They're there to help us over to the other side. It really works well. But it changes with every person. I tailor it to suit the individual person." For example, Rev. DeMarco's mother had "adopted" Brad Anderson before her death. "I told Brad that she would be there for Brad when he made his transition."

Rev. DeMarco has learned a great deal through her AIDS Ministry. "It's taught me that not all healings are physical, and at no time are we ever alone. The God I used to believe in that was so far away, I now find in each person I deal with. That inner light is there, and that's the Christ light. After all the anger you deal with from people with AIDS, and after you help them with that anger, I've found they can go on and live a joyous life, even in the face of dying. I'm convinced that three-quarters of our healing comes when we reach out to others." ▼

Treatment Briefs

By David Gold

[The following four articles are reprinted with permission from
GMHC Treatment Issues, August, 1994, Volume 8, Number 7]

Promising Lymphoma Treatment

MGBG, a product developed by Sterling Winthrop, may show promise as a treatment for AIDS-lymphoma, according to a report at the Thirteenth Annual Meeting of the American Society of Clinical Oncology held in Dallas from May 14 to 17, 1994 (abstract 11). In the study, led by Alexandra Levine, M.D., of the University of Southern California, MGBG was given intravenously (600 mg) on day one, day eight, and then every other week to fifteen patients with relapsed and refractory AIDS lymphoma.

A median of five doses of MGBG was given. Two complete responses and three partial responses were reported. Thus five of fourteen patients (36 percent) saw some response to the drug. The average CD4 count was 90 at the trial's start, and median survival was 4.3 months. MGBG also was associated with some weight gain. Toxicities were "very mild" according to Dr. Levine and included skin flushes during infusions, nausea and vomiting (three cases), and euphoria.

Standard chemotherapy for lymphoma is often difficult to tolerate, particularly for those with advanced HIV disease. This small study suggests that MGBG may be of some benefit in treating AIDS-related lymphoma. Larger trials should be started without delay. These studies should consider an arm with a higher dose to see if the response rate can be improved. An expanded access program for those who have failed standard therapy may also be appropriate.

TAG Issues KS Report

The Treatment Action Group (TAG) has issued "The KS Project Report: Current Issues in Research & Treatment of Kaposi Sarcoma." The 85-page document, written by Michael Marco with Martin Majchrowicz, is extremely informative and an impressive example of effective and targeted treatment activism.

Copies of this report can be obtained by sending US \$10 (ten dollars) to TAG, KS Report, 147 Second Avenue, Suite 601, New York, NY 10003.

Oral Ganciclovir for CMV Prophylaxis

An initial look at data from an ongoing study of an oral version of ganciclovir reportedly suggests that the drug may help prevent the onset of CMV disease. The study, which enrolled over 700 HIV-positive individuals with less than 50 CD4 cells and a positive CMV viral titer, randomized patients to either 1,000 mg of ganciclovir taken by mouth three times daily or placebo. According to Linda Thomas, a spokesperson for ganciclovir's developer, Syntex Laboratories, the trial's Data Safety and Monitoring Board did its first regular review in July and determined that the data showed "highly significant evidence of efficacy plus a trend towards improved survival which reached near statistical significance." The Board recommended that the placebo portion of the trial be eliminated and that all trial participants receive the drug.

Before this new data was available, Syntex had already submitted a new drug application requesting that the FDA approve oral ganciclovir as a maintenance therapy in people who had already experienced an instance of CMV retinitis. The company is likely to amend its application to add CMV prophylaxis before any symptoms appear to the proposed indication. While the FDA has this under consideration, it is hoped that some expanded access program for CMV prophylaxis can be initiated.

No Boost for AIDS Research Budget

A U.S. Senate appropriations subcommittee failed to increase the National Institute of Health's AIDS research budget. The subcommittee left research funding at the same level as the House (\$38.5 million below President Clinton's request). It also reduced the House's appropriation for AIDS prevention by \$37.7 million and increased care money under the Ryan White Act by \$8 million. Richard Ford, of Senator Patrick A. Moynihan's (D-NY) staff, contacted *Treatment Issues* proudly reporting that Senator Moynihan had written to Senator Harkin, (chair of the appropriations subcommittee) requesting that Ryan White funds not be reduced in the 1995 budget. Ford, who is Senator Moynihan's chief staff person on AIDS, expressed both surprise and skepticism when it was pointed out to him that the AIDS research budget was part of the NIH authorization and not part of Ryan White funding for AIDS care.

NAPWA Offers FAX Info

The U.S. National Association of People with AIDS (NAPWA) has initiated a fax service, providing the latest information to AIDS care providers and people living with HIV. NAPWA Fax is a fax-on-demand system that will provide free and timely information about:

- * Funding alerts for public and private grants
 - * Health and treatment needs
 - * Insurance and benefits
 - * Legal issues...and much more
- NAPWA Fax provides an immediate response 24 hours a day, seven days a

week. Simply dial from the phone on your fax machine to hear a catalogue of topics and to order information from the automated voice system. Documents requested will be automatically faxed back to you. The NAPWA Fax number is 202/789-2222. ▼